

status Report

The Quarterly Newsletter on
Disability Issues in Alberta

THE PREMIER'S COUNCIL ON THE STATUS OF PERSONS WITH DISABILITIES

FEBRUARY 2000

inside

Open Houses Offer Great Start	2
Report Raises Concerns	3
Neurotrauma Revisited	4
Resources for Non-Profits	5
Barrier Free Building	6
Help Available for Little Known Syndrome	8
Chip Restores Communication	9
Weighing It Up: Making the Most of Exercise Equipment	10
Ability Place Promises New Partnerships	11

Take the "L" Train

Wheelchair and scooter users, long-frustrated with the less than ideal accessibility of Edmonton's LRT system, finally have something to cheer about. Several LRT cars were recently retrofitted with automatic ramps designed to improve access for people with disabilities. Additionally, accessibility improvements have been made at some LRT stations, and more changes will come in the next three years. See story on page 7.



Challenger Park Gets Go-ahead

Disability-focused sports facility slated for Calgary in 2000

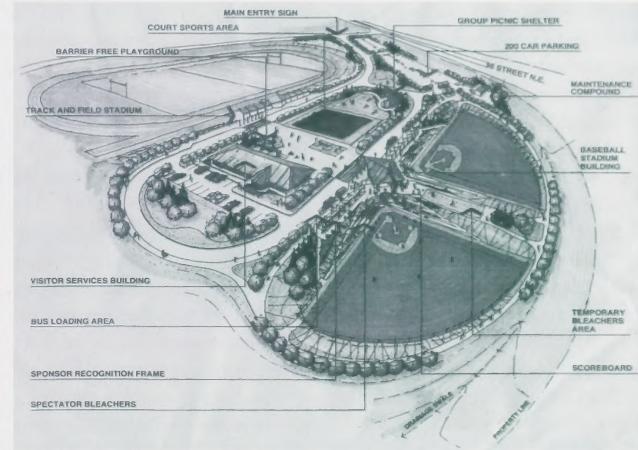
People with disabilities may soon be able to enjoy a state-of-the-art, totally accessible, multi-sport facility in Northeast Calgary.

Developers say that, unlike other sports facilities which are modified after the fact, Rotary Challenger Park will be the first multi-sport facility in North America to be designed from the ground up for athletes with physical or developmental disabilities.

Plans for phase one, slated for completion by this Fall, include baseball and softball diamonds, a stadium building, a playground, barrier free parking for 200 cars and six buses, and a specialized drop-off area. Subsequent phases could include a soccer field, a track and other facilities.

"Challenger Park is a launching pad to build confidence—social integration and overall performance can enrich the lives of all people with disabilities," says Peter Josty, Vice Chair of the Rotary Challenger Park Development Society. "We're aiming for this to be a world class, multi-use facility which will serve as a showcase for the disabled in Calgary. It's the first time anybody's done this, to the best of our knowledge. So we're hoping that people will see this and imitate this across the country and across North America."

Josty says that the estimated



number of potential users in the Calgary area exceeds 100,000. He adds that there is great opportunity for the facility to be not only an athletic park, but a focal point for Calgarians with disabilities. Two possibilities on the table include the addition of a sports medicine clinic and office space for user organizations.

As the name implies, Calgary's 12 Rotary Clubs are taking a lead role in organizing the project. Other partners include the Calgary Airport Authority, Parks Foundation Calgary, Calgary Parks & Recreation, and many disability-related organizations.

Currently, the partners are attempting to develop a governance model suitable to all user groups. Another priority is a corporate fundraising campaign.

"We need \$4.5 million—that's

our total project," explains Josty. "That consists of \$3.5 million to construct our project, and \$1 million for an endowment fund that would be used to generate income for the ongoing maintenance." He adds that current commitments amount to 10% of the goal.

To date, the most significant contribution to the project has been the Calgary Airport Authority's donation of the land—nine acres located at the junction of 36th Street and McKnight Boulevard in Northeast Calgary.

Although subject to Calgary City Council approval, it appears likely that Calgary Parks and Recreation would operate the facility when completed.

For more information, please contact Peter Josty by telephone (403/249-0191) or by e-mail (p.josty@home.com).

Open Houses Offer a Promising Start

The Premier's Council is in the preliminary stages of developing a Provincial Disability Strategy—an overall umbrella policy to guide government and agencies when developing policy that impacts Albertans with disabilities.

Last November, the Council began work on this ambitious project by holding public meetings in six Alberta centres: Bonnyville, Grande Prairie, High Level, Edmonton, Calgary and Medicine Hat. The goal was simple: gain an understanding of what Albertans with disabilities want to see included in such a strategy.

A total of approximately 425 people attended the meetings. Generally, the sessions were well received and the discussion was open and lively. It should be noted, however, that many of the people in attendance at the Calgary meeting expressed anger and frustration over a perceived lack of important government services.

The format was similar for each meeting. Following a presentation of our preliminary vision for such an encompassing Strategy, participants were asked to work in small groups to arrive at answers to specific questions posed by the Council.

Not surprisingly, the observations and issues were similar at each meeting. Here's an abbreviated summary of responses.

What is very positive about the Strategy?

We were greatly encouraged by responses to this question. The Council was praised for seeking public input, its cross-disability approach and its attempts to increase its visibility. Respondents also clearly supported the proposed Strategy's focus on coordination of all levels and departments of governments.

Equally well-supported was the proposed action-oriented approach, whereby specific tools are used to measure progress in programs and services.



What needs more work?

Respondents indicated that the Strategy remains somewhat unclear, and that they would like to see a clearer picture of what it would look like and how it would work. Responses to this question also reinforced the Council's commitment to raise awareness of its role and work—and of the abilities of all Albertans with disabilities. Specific recommendations pointed to the need for the Council to develop a comprehensive communications strategy, which the Council has already begun work on. People also responded to this question by expressing concern over perceived lack of service in key areas. For example, issues raised included the need for more employment, housing and transportation options; stronger building code enforcement; increased access to sign language interpreters; access to information about services; and understanding of the unique needs of people with disabilities living in isolated communities.

What concerns have not been addressed by the Strategy?

Many people expressed concern over eligibility and current levels of income support programs such as AISH. Others called for the Strategy to encompass human rights and aboriginal issues. Another common response highlighted the need for the Strategy to focus on building partnerships in the public, at all levels of government and in the business community. Finally, many responses indicated the

need for detailed explanation about the Strategy—how government policy will be influenced, where funding will come from, how it will be implemented, and how goals will be verified.

What should be in the Provincial Disability Strategy?

Respondents provided many excellent specific recommendations which will be incorporated as development of the Strategy continues. These included clearly defining what constitutes disability, incorporating a position of basic human rights and equity of access, addressing the larger issues such as financial support and employment, obtaining a commitment to free flow of information between government and people with disabilities, raising public awareness of disability, and involving people with disabilities at the grass roots level in the decision-making process.

How can the Premier's Council improve networking and communication?

The Council anticipated that many respondents would feel strongly about improving overall communication of the Council's work and of disability issues in general. We received excellent recommendations in response to this question. Specifically, we were told to work together with all other partners, create more opportunities for people with disabilities to voice their views through public forums and through inclusion on working committees, create more public awareness of the Council's work through advertising, create one-stop information referral services, and teach self-advocacy at the grass roots level.

In closing, we learned a great deal from these open houses. We would like to express our gratitude to those who took the time to attend and provide us with your thoughtful responses. Your input will be included as we continue to develop this Strategy, and more details will follow in future issues.

For a complete summary report of the open house meetings, please call us at 800/272-8841.

Status Report

Editors: Elaine Chapelle, Carmen Grandmont, Cliff Bridges

Design and Production: Bridges Communications

Canadian Publication Mail Agreement No. 1518941

Status Report is published quarterly by the Premier's Council on the Status of Persons with Disabilities and is intended to provoke discussion of issues concerning persons with disabilities. This publication is also available on audio cassette by contacting our office at:

Premier's Council on the Status of Persons with Disabilities
250, 11044-82 Avenue
Edmonton, Alberta T6G 0T2
Phone 780/422-1095 or
Toll Free 800/272-8841
(Voice or TDD)
Fax 780/422-9691
E-mail: pcspd@planet.eon.net
www.premierscouncil.ab.ca

Readers' feedback is always appreciated. Please send to: The Editor, **Status Report**, at the above address. For permission to reproduce editorial contained in **Status Report**, contact the Editor.

The opinions expressed in **Status Report** are those of their authors and are not necessarily those held by the Premier's Council on the Status of Persons with Disabilities.

Home Care Study Raises Concerns

A recently completed report by researchers at Queen's University suggests that, while Canadians are becoming increasingly comfortable and dependent on home care, such services are not being supported by health policy makers.

The 80-page report, entitled *Putting a Face on Home Care*, provides evidence that health care restructuring has led to institutions sending people home quicker with the assumption that adequate, consistent home care services are in place when, in reality, they're not.

The report's authors write that home care in Canada is "under-funded, undervalued and overstressed...increasing the burden on recipients of home care and their care givers."

The report contains a number of key findings—many surprising—and recommendations for change (see sidebar). It also contains a call to action—the authors

Key Findings

- Lack of leadership and cohesive strategy to guide improvement
- Home care workers are overworked and stressed
- Home care services are consistently under-funded
- Informal caregivers, i.e., family members, faced with increasing burden
- Non-profit and volunteer organizations unable to cope with demand
- Policies being introduced which decrease eligibility to service
- Increasing number of for-profit organizations cutting into service levels
- Lack of knowledge of home care and who is eligible
- Lack of research and knowledge to guide home care policy.

Policy Recommendations

- Establish country-wide task force on home care
- Establish a council(s) on home care
- Provide greater support to non-profits involved in home care
- Increase corporate responsibility
- Support information technology specific to home care
- Develop supportive housing to bridge gap between institutions and home
- Commit to research of home care

suggest that all stakeholders, including governments, service providers, individual workers and service recipients need to work together in order to create a more

efficient, fully-funded and responsive home care system.

The report's importance is amplified by a number of other credible studies which point to

both the effectiveness and efficiency of home care as an alternative to traditional institutional care. For example, a study recently published in the *Journal of the American Medical Association* clearly illustrated that elderly patients sent home to recover from common health problems improved faster with home care support than those without home care support, resulting in significant cost savings.

Putting a Face on Home Care was commissioned by Canada's Association for the Fifty-Plus (CARP), which represents more than 400,000 Canadians aged 50 and older. The report is based on information collected across Canada, and includes input from more than 250 Canadian organizations involved in home care, as well as health associations and unions.

For more information, or to obtain a copy of the report, contact CARP at 416/363-8748.

Snapshot: Home Care in Canada

500,000 Canadians currently receive home care

2.4 % of Canadians receive some form of home care in their lifetime

\$2.1 billion is spent each year on home care

75% of Canadians released from hospital could benefit from some home care services

Over 50% of persons requiring help with daily living are not receiving any home care

One in eight Canadians report being a "caregiver" to a family member

Source: Statistics Canada

U.S. Congress to Tackle Home Care

Legislation soon to be introduced in the U.S. Congress would allow some two million Medicaid recipients presently living in institutions to receive services at home if they choose.

The Medicaid Community Supports Act (MiCASSA) was introduced in the Senate in November by Democrat Senator Tom Harkin and Republican Senator Arlen Specter. American disability activists expect the proposed legislation to be introduced in the Congress early this year.

MiCASSA is very similar to a bill that was considered—and subsequently passed on—by Congress last year. The new bill is expected to have much broader support when it makes its way into Congress. One of the main reasons for this is its inclusion of people with developmental disabilities, whose right to receive community-based services was confirmed by a recent Supreme Court decision.

The U.S. Congress appears to be increasingly sensitive to disability issues. In December, President Bill Clinton officially signed into the law the Work Incentives Act, which will allow millions of citizens with disabilities to keep Medicare and Medicaid health coverage when they take a job.

That bill was sponsored by Democrat Senator Edward Kennedy and Republican Senator James Jeffords.

Neurotrauma Proposal Revisited

Is Alberta about to follow the lead of several U.S. states and impose a traffic fine surcharge to support brain and spinal cord injury research?

For several years, the Alberta Neurotrauma Initiative has been attempting to find a way for Albertans to support spinal cord and brain injury programs. Their efforts have resulted in only sparse funding levels, but a breakthrough may come in the near future.

The Alberta Neurotrauma Initiative, an offshoot of a larger initiative spearheaded across Canada by the Rick Hansen Institute, is a coalition of stakeholders including the Alberta Division of the Canadian Paraplegic Association (CPA), The Alberta Paraplegic Foundation, and the Brain Injury Association of Alberta. Collectively, these organizations have been attempting to impress upon government the tremendous financial impact of neurotrauma—and that funding to support research, rehabilitation and prevention programs could significantly reduce the impact.

When it was formed three years ago, the Alberta Neuro-

trauma Initiative lobbied the Alberta government to redirect a portion of relevant traffic violations to a "neurotrauma fund." At the time, the idea met with resistance, and the Alberta Government elected to provide limited grant funding instead.

But Neil Pierce, Executive Director of CPA Alberta, is convinced that government is warming to the idea—or other avenues of funding the initiative.

"We're hoping that we get key ministers together," says Pierce. "We have the invitation—the invitation has been extended by government. We're just trying to coordinate a meeting for late January. We hope they'll respond to the call for action."

Pierce maintains that a traffic fine surcharge would be an excellent way of supporting neurotrauma programs, but adds there are several other funding methods being explored, including a surcharge on vehicle insurance premiums or registrations.

There's little doubt that one



CPA's Pierce: "We're hoping that we get key ministers together. We hope they'll respond to the call for action."

of government's priorities will be to ensure that funds raised be administered and directed responsibly and fairly. Pierce says stakeholders have anticipated and responded to this concern. "The final evaluation of the Neurotrauma Connections '99 symposium that's being mailed out proposes the establishment of the 'Alberta Neurotrauma Board.'" He says the proposal contains suggested mandate and

roles, adding that the proposed structure would be very similar to that of the Alberta Cancer Board.

Meanwhile, the concept of mandatory, publicly-supported neurotrauma research continues to expand in the United States. The latest state to take action is New Jersey. In September, Governor Whitman signed legislation that will fund spinal cord injury research with a \$1 surcharge on all motor vehicle fines in the state.

The law is expected to raise \$3.2 million a year.

At the signing ceremony, Whitman paid tribute to paralyzed actor Christopher Reeve, who lobbied for the legislation. "Chris, I have a debt of gratitude for everything you've done," said Whitman. "Everyone here feels your commitment."

The state of New York passed a similar bill earlier this year, and Illinois recently introduced a traffic-fine related bill. Numerous other U.S. states have had this type legislation in place for several years.

Athletes Furious with International Paralympic Committee

Drastically stricter qualifying standards for next year's Sydney Paralympics have Canadian athletes and coaches fuming. Their anger has been brewing for some time, but it recently boiled over in a recent issue of the *Coaches Forum*, an online newsletter available to anyone involved with Paralympic preparations.

In the issue, wheelchair track star Jeff Adams was one of those

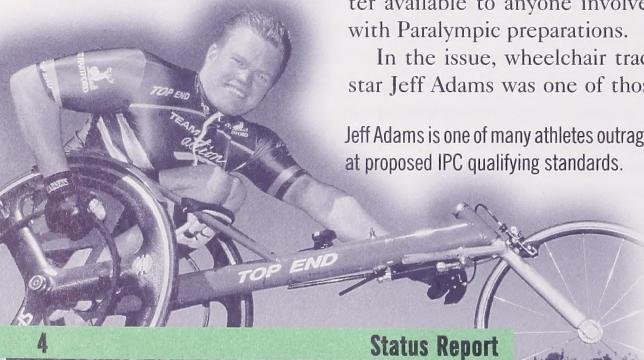
Jeff Adams is one of many athletes outraged at proposed IPC qualifying standards.

who vented their frustration. "The standards that the IPC is supporting...are not realistic; they propose entry standards that vary from between 95% and 110% of existing world records, and if allowed to stand will result in the cancellation of some events," wrote Adams, arguably Canada's best known Paralympians.

"These decisions surrounding the selection standards affect the careers and lives of athletes who have sacrificed and dedicated themselves to the pursuit of the Paralympic ideal. If decisions continue to be made without regard for the interests of the athletes, perhaps it is time to investigate the realistic option of forming a new international federation that is more athlete-centered in its approach, and more logical in its decision making process."

Similar condemnation of the proposed standards has come from athletes and coaches from the United States and around the world.

At press time, the IPC remained firm on implementation of the standards.



Billionaires Battle Polio

Billionaires Bill Gates and Ted Turner have made an huge contribution to the World Health Organization's (WHO) quest to eliminate polio.

At a Geneva news conference in December, The World Health Organization, Rotary International and the United Nations Children's Fund announced that the Bill & Melinda Gates Foundation and Ted Turner's United Nations Foundation donated \$50 million and \$28 million respectively in a unique partnership to support the efforts to eradicate polio.

The Bill and Melinda Gates Foundation was set up by the soft-ware tycoon and his wife to increase access to education, technology, and health services. The foundation pledged nearly \$1 billion in donations in 1999.

Meanwhile, broadcast mogul Ted Turner's donation is part of his pledge to donate \$1 billion over 10 years to United Nations initiatives designed to benefit the environment and women and children's health.

"By working together we can make existing vaccines available to all the world's children. The people of this world can and should do this together."

Polio is a disease that mainly affects children and causes life-long paralysis in varying degrees. There is no cure but a few drops of vaccine will protect a child for life. While the polio vaccine has all but eradicated the disease in North America and Europe, it remains a threat in many devel-

oping countries in the Mideast, South Asia and Africa.

The combined \$78 million donated by Gates and Turner will help vaccinate millions of children during mass immunization campaigns that are the backbone of the effort to end the dreaded disease. The donations will primarily be used to strengthen the vaccine delivery infrastructure and to track where the disease is occurring.

"Melinda and I are committed to a world without polio and are proud to be a part of this global effort," said Gates. "By working together we can make existing vaccines available to all the world's children. The people of this world can and should do this together."

"The United Nations Foundation is delighted to work with the Bill & Melinda Gates Foundation in supporting the polio eradication initiative," said Turner. "Our combined efforts will move us into a polio-free world in the new millennium where children are never crippled by this terrible disease."

"We are on track to eradicate polio," said WHO Director-General Dr. Gro Harlem Brundtland. "One of the biggest challenges we now face is raising the necessary funds to finish the job on time. With this kind of contribution, a polio-free world is within reach and one of the world's largest health initiatives can be brought to a successful conclusion. I would like to thank Bill and Melinda Gates as well as Ted Turner for these gifts."

WHO reports that, with these gifts, the remaining funds needed to finish the job of eradicating polio total US \$400 million through to 2005—the target for officially certifying the world as polio-free. Immunization and surveillance activities will need to continue at least until that date.

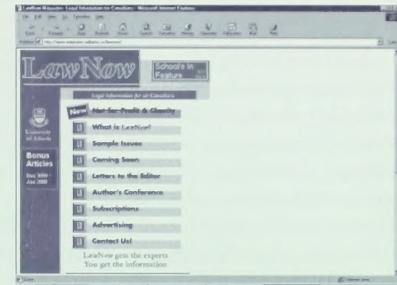
Legal Answers Online

The answers to your organization's legal concerns and questions might be found on a new online resource.

The resource is actually a new edition to the University of Alberta's Faculty of Extension *LawNow* website. The new addition was developed by the University of Alberta's Legal Studies Program and the Faculty of Extension Legal Resource Centre, publishers of the *LawNow* magazine and website.

The site contains three parts: a section containing reprints from *LawNow* Not-for-Profit and Charity, a section containing FAQs (frequently asked questions and answers), and a section containing links to other relevant sites.

Information contained at the website relates to standard issues for non-profits, including insurance and liability, professional development, and taxation. For details, check the website (www.extension.ualberta.ca/lawnow/nfp).



Muttart Foundation Offers Computers

The Muttart Foundation, with the assistance of an anonymous donor, is offering charitable organizations in Alberta and Saskatchewan new Y2K compatible computer systems.

The computers, which are available until the funds are exhausted, will include Microsoft Windows 98 2nd Edition, Microsoft Office 2000 Professional, anti-virus software, and a basic form of data backup, such as a Zip drive.

The computers are intended to help organizations replace outdated, non-Y2K compliant hardware. Preference will be given to those organizations which have a genuine need for new computer equipment so that they may operate more effectively. Specific conditions that applicants must meet include:

- Organizations must be a registered charity in either Alberta or Saskatchewan
- The primary purpose of the organization must not be arts-related
- A copy of the organization's audited financial statements must be included
- A copy of the organization's Year 2000 audit/inventory, showing the uses (i.e., word processing or accounting) and compliance/non-compliance status of all systems, must be included.

The Muttart Foundation was incorporated as a private charitable foundation in 1953 by the late Merrill Muttart and Gladys Muttart. Working with a small staff, the Foundation's Board of Directors considers applications for grants from registered Canadian charities. The Foundation's assets total approximately \$60 million.

For more information, contact the Muttart Foundation in Edmonton at 780/425-9616.

Barrier Free Building Design

Part one of a four part series on incorporating accessibility during construction and renovation of publicly-used buildings

For the past five years I have been practicing architecture on my own, focusing my attention on barrier-free design. During this time, I've been exposed to the most common and difficult accessibility issues relating to our built environment, and I've learned how to make it easier for all people, regardless of ability, to move about in it.

Our aging population is ever increasing in size. The need to accommodate seniors, along with persons with physical, sensory and mental disabilities, often plays a key role in determining the difficulty and expense of any specific building renovation.

Over a series of four articles, I will discuss important accessibility topics as they relate to new construction and building renovation work. I've attempted to keep the material generic so that it can be used as a starting point for virtually any new construction or renovation work. The first three articles deal with specific issues: Accessible Parking, Ac-

cessible Building Entrances, and Accessible Interiors (with a focus on washrooms). I'll conclude with an article providing a more general comment on designing cities to better accommodate persons with disabilities.

Part One: Painless Parking

Critical for making the exterior area of any building accessible to persons with disabilities is pro-

viding a required number of accessible parking stalls (this will depend on the building's use) and a barrier-free path of travel to the building's interior.

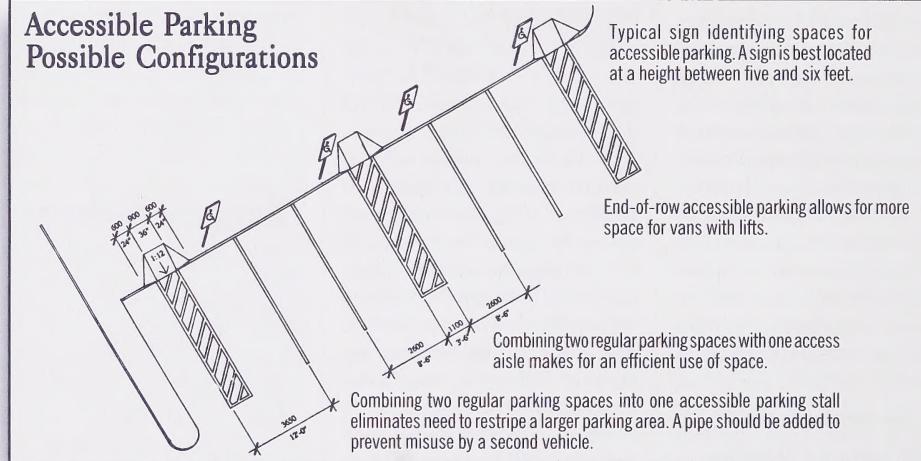
According to the National Building Code (NBC), a parking stall for use by individuals with disabilities shall be at least 3.7 m wide and be situated on a firm, slip resistant and level surface; it shall also be located near

the public entrance and clearly marked as being for the use of persons with disabilities only. The checklist in the sidebar at the bottom of the page is what I use to help me design new buildings or analyze existing buildings in order to make recommendations towards renovations.

During renovations, it can often be difficult—and expensive—to modify the parking lot to incorporate accessible parking stalls. An alternative to repainting the lines in the entire parking lot is to combine two existing parking stalls to provide the required 3.7 m (12'-0").

Currently, however, the biggest challenge in developing positive accessible parking is not one of identifying critical sizes,

Accessible Parking Possible Configurations



Accessible Parking Checklist

- How many accessible parking spaces are there? Does this seem to be enough?
- Are accessible parking spaces located in the same place as all other public parking?
- Are the accessible parking spaces as close as possible to the main accessible entrance (within 30 m (100'-0") of the entrance)?
- Can a user with a disability get from an accessible parking space to a barrier-free path of travel without travelling through an automobile traffic area?
- Is there a barrier-free path of travel from the parking area to the building entrance?
- Is there a curb cut, leading to a sidewalk, at each accessible space or pair of spaces?
- Is there a sign at each space or pair of spaces? Do any signs read "Wheelchair Access Only" or "Van Accessible"?
- Is the international symbol for accessibility both on the ground surface and upright on a wall, fence or pole?
- Is the sign at least 300 mm (12") by 600 mm (24")?
- Is the sign installed at a height of at least 1.5 m (5'-0") from the ground/floor surface to the centre of the sign?
- Is the pavement symbol at least 1 m (3'-3") long? Is the pavement symbol in a colour strongly contrasting with the background pavement?

- Is each accessible parking space 3.6 m (12'-0") wide or, are there two 2.4 m (8'-0") wide spaces with a 1.2 m (4'-0") wide aisle between them?
- If accessible parallel parking spaces are provided, are they adjacent to the barrier-free path of travel and are they at least 3.6 m (12'-0") wide by 7.3 m (24'-0") long?
- If bollards are used for traffic control, are they spaced at least 910 mm (3'-0") apart? Are they color contrasted to adjoining materials and are they well lit at night?
- Are parking metres or block heaters located in the barrier-free path of travel as a potential hazard to those individuals with sight or mobility limitations?
- If canopies or overhead supports are provided, is there at least 2.4 m (8'-0") headroom for vans used by persons with disabilities?
- If underground or parkade parking exists, is the space large enough to accommodate a modified van for an individual in a wheelchair?
- If the accessible parking space is intended for vans, is the width, including the access aisle at least 4.6 m wide (15'-0")?
- If the accessible van parking is in a parallel parking space, is it at least 2.6 m (8'-6") wide by 7.4 m (24'-3") long?
- Is the height clearance at least 2.75 m (9'-0") at the parking space and along the vehicle access and egress route?

locations or signage, but one of polities. Simply stated, we need to provide a greater number of accessible parking stalls by Code.

Increasingly, more people are being allowed to use accessible parking stalls—a direct result of our aging population. But it's safe to say that the majority of persons who use accessible stalls aren't wheelchair users; rather, they move slowly because of some other mobility limitation.

The problem with creating more "wide" accessible parking stalls is that these larger stalls take up more space and require more land. This naturally increases the construction cost of any building project. The reality is that we don't need more stalls designed for persons in wheelchairs. Instead, we need more accessible parking for non-wheelchair users. The solution is to create two types of accessible parking stalls:

Family Type Parking Stalls should be of a standard size but be located near the building entrance. Seniors, persons with mobility limitations and persons with small children would use these stalls. **Wheelchair Only**



"Wheelchairs Only" parking stall at London Drugs, Southside Edmonton.

Parking Stalls should be larger in size and be used only by persons in wheelchairs.

This approach has been taken successfully in several locations throughout Alberta—for example, a London Drugs store on Edmonton's southside (see photo).

Regarding access to the building entrance, according to the NBC, an exterior walk that forms part of a barrier-free path to travel shall provide a continuous permanent, firm and slip resistant surface with a gradient not ex-

ceeding 1 in 20; if the gradient is greater than 1 in 20 it shall be designed as a ramp. It shall also have a minimum uninterrupted width of 1100 mm free from obstruction for this full width to a minimum height of 1980 mm.

If renovations to existing exterior walks are necessary, it's recommended that its minimum width become 1500 mm. This allows two individuals in wheelchairs to move along side one another and for a person in a wheelchair to turn around. The

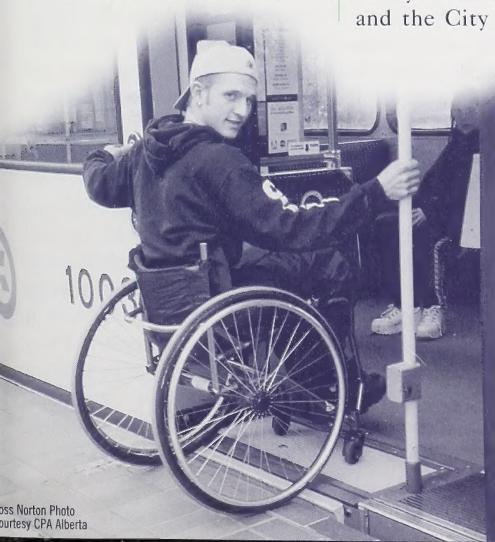
grates of any catch basins should be perpendicular to the path of travel with less than 13 mm of space between grates; this will help prevent wheelchair wheels and canes from getting caught in them.

For further research, consider the design of curb cuts, benches, mailboxes, public telephones and drinking fountains.

Architect Ron Wickman has operated his Edmonton-based practice since 1995. Ron's interest and expertise is in barrier-free design; he also has a special interest in multi-family housing and urban and community planning. He specializes in providing consulting services for persons with disabilities and for projects focused on affording individuals with disabilities greater choices for independent movement. He is also president of Finalta Designs Inc., a design-build firm committed to providing affordable, accessible and adaptable housing. Finalta's first built project is located in north Edmonton, a result of winning a City of Edmonton Affordable Housing Demonstration Project Competition. You can reach Ron at 780/430-9935.

Edmonton Transit Upgrades LRT Accessibility

Wheelchair and scooter users have complained about the inaccessibility of the City of Edmonton's Light Rapid Transit (LRT) system since it was first introduced.



It took nearly two decades, but the problem is finally being resolved with the installation of automatic ramps in LRT cars. The ramps were recently added to three LRT cars, and the City has pledged to

have all of the system's cars retrofitted by the year 2003.

The ramps bridge the difference in height between the car and deck of the station, which can be as much as ten centimetres depending on the car's load and which station you use. They're located in the middle doorway on each side of the cars. The accessible doorways are marked with a large wheelchair decal and have a large, round, lit button on each side of the door, just below the normal access button. It's difficult to miss the ramps themselves—they're bright yellow.

The city has made other changes in the centre of the retrofitted cars to improve accessibility and customer travel comfort. The curve of the stanchion in the doorway has been

reduced, and it's been painted bright yellow, too. The double seats at the centre of the car have been replaced by bench seats to increase the space for scooters and wheelchairs. Customers using this section of the car won't be so crowded.

The City has also completed some accessibility improvements at LRT stations, including an increase in the number of handicapped parking stalls, installation of handrails on some ramps, installation of automatic doors, and upgrades to the elevators.

The schedule for the LRT equipped with the access ramps is available by calling BusLink at 780/496-1600 and entering the four digit number for the LRT station where you want to catch the train.



Help Available for Little Known Syndrome

Few people have ever heard of Prader-Willi Syndrome, or PWS. In recent years, however, more information has surfaced about this syndrome. Various interventions have been identified to ease its effects, and there are groups dedicated to providing support and information related to it.

PWS has a world-wide incidence of about 1 in 10,000 and affects people of all races and both genders. It's caused by a non-inherited genetic defect. Specifically, at least four genes are missing from part of chromosome 15. These genes have been identified for their effects on appetite, emotion, growth and sexual development.

Newborn children with PWS are extremely hypotonic. Accordingly, they lack the ability to suck or swallow properly. They also have a very weak cry (or no cry at all), and experience delays in sitting, walking and talking. At this stage, they also have little interest in food.

When children with PWS are between two and fours years old, they enter a second phase which continues throughout life. At this time, the lack of the gene for appetite control causes an uncontrollable appetite. The affected individual never feels sated. This is such a strong psychological force that it can completely overcome the power of reason.

Metabolism is also affected, and without strict dietary control, obesity can't be avoided.

In particular, access to money must be controlled, since money easily becomes food.

Another glaring symptom is lack of emotional control which can be expressed in violent temper tantrums. Typically, people with PWS also have incomplete sexual development, varying degrees of developmental or physi-

cal disability, small hands and feet, short stature, and a high pain threshold which can mask more serious conditions.

While the intelligence of affected individuals varies as much as in the general population, people with PWS typically have learning difficulties—particularly with abstract ideas.

As little as two decades ago, this combination of symptoms led to life expectations of less than 20 years. Today, many people with PWS have a much more normal life expectancy.

There is no known cure or specific treatment for PWS. But the effects of the syndrome can be minimized through genetic counselling, special schooling, psychological guidance and a controlled living environment. In particular, access to money must be controlled, since money easily becomes food.

Recently, growth hormones have proved to be beneficial for a number of people with PWS.

Early diagnosis is extremely

important. When identified, appropriate measures may be taken to stimulate infants with PWS, which may possibly lead to decreased developmental disability. As well, appropriate dietary patterns are more effective if implemented earlier in life, lowering the risk of obesity and its possible consequences—diabetes, respiratory conditions and scoliosis (curvature of the spine).

Regardless of interventions, PWS is a lifelong reality, and stress on families becomes extreme. The constant pressure of food control and temperamental behaviour affects all family members. Parents have to be assertive in seeking both medical and non-medical help, and there should be respite care available to both parents and the person with PWS.

Since 1986, the Prader-Willi Syndrome Association of Alberta has been available to provide support and information for families experiencing PWS. For more information, contact the association at 403/274-7486.

Sexual Health Council Offers New Disability Resource

The Canadian Male Sexual Health Council recently partnered with several Canadian disability organizations to launch a new information resource aimed at creating a better understanding of erectile dysfunction (ED).

"There are a number of medical conditions that can cause ED," says Dr. Gerald Brock, Chairman of the Council. "ED is the most common sexual problem reported by men with spinal cord injury, diabetes, multiple sclerosis and prostate cancer."

Brock says this is the reason the Council developed a series of brochures focused on ED and these conditions. Each brochure defines ED, explains the link between the associated condition and ED, and outlines available treatment options.

The goal of the brochures is to encourage men to approach their doctors to discuss any sexual health problems they're experiencing, including ED.

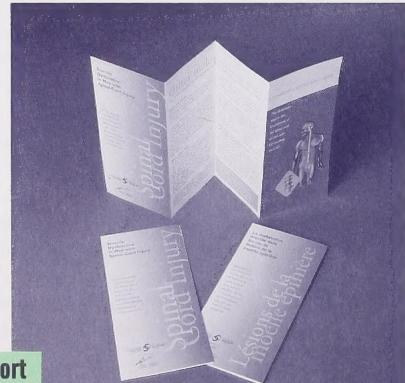
"The messages that ED is a serious health problem and is most commonly associated with an underlying medical condition must be reinforced," says Brock. "ED is a medical condition that affects the quality of life of men with ED and their partners."

The Canadian Paraplegic Association, the Multiple Sclerosis Society of Canada, and the Canadian Prostate Cancer Network worked with the Council on the undertaking.

The brochures are available by calling Educare at 800/672-9222.

A grant from Pfizer Canada made the development of the brochures possible.

The Canadian Male Sexual Health Council is a nationally represented multidisciplinary group comprised mainly of physicians with a significant interest in male sexual health. Their mission is to raise awareness of sexual issues between partners and to heighten recognition of male sexual dysfunction as a significant health problem.



Brain Chip Restores Communication

Science fiction has become reality at Atlanta's Emory University, where two researchers have developed a method to allow a completely paralyzed person to command a computer by simply thinking.

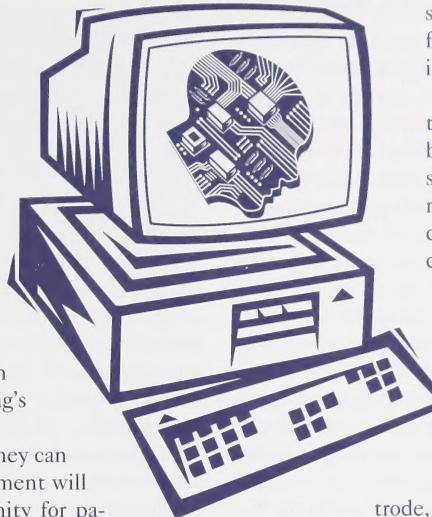
The technology, which uses tiny implanted electrodes to establish a direct connection between brain and computer, enables the users to operate the computer to communicate and interact with their environment.

Roy E. Bakay, M.D., and Phillip R. Kennedy, M.D., reported in November that they had successfully tested the technology with two patients at Emory University Hospital—one with amyotrophic lateral sclerosis (ALS, or Lou Gehrig's disease) and one with brainstem stroke.

"A person can interact with the world if they can use a computer," said Bakay. "This development will open up a tremendous amount of opportunity for patients who have lost the ability to move and talk because of stroke, spinal cord injury or diseases like Lou Gehrig's disease."

The researchers implanted the electrodes into the motor cortex of the brain using a tiny glass encasing. The glass contains neurotrophic factors, which attract and stimulate brain cells to merge with the electrode and form contacts (this takes several weeks for this to occur). Recording wires are placed inside the glass cone to pick up the electronic signals from these brain cells and transmit them through the skin to a receiver and amplifier outside of the scalp. The system is powered by an induction coil placed over the scalp; no wires go through the skin.

The signals are then used to control the computer cursor in the



same way a computer mouse is moved back and forth. The user learns to will the mouse to move in various directions.

"The trick is teaching the patient to control the strength and pattern of the electric impulses being produced in the brain," says Bakay. "After some training, they are able to 'will' a cursor to move and then stop on a specific point on the computer screen. If you can move the cursor, you can stop on certain icons, send e-mail, turn on or off a light and interact with the environment."

"Our present patient, who is at the Atlanta VA Medical Center, is paralyzed except for his face due to brainstem stroke following a heart attack; he is dependent on a ventilator and cannot speak, yet he is fully alert and intelligent. This patient, who was implanted five months ago with the electrode, can move the cursor from icon to icon in a horizontal direction. As each icon is encountered, a phrase is spoken by the computer."

Bakay says he wants to move the research beyond communication to actual muscle control. "Our hope is that soon we will be able to get to the point that we can connect the neural signals to a muscle stimulator in the patient's paralyzed limb and have them move that limb using the same principle that they use to move the cursor."

The implanted electrode technology was developed and patented by Kennedy while at the Georgia Institute of Technology. It has been tested in animals over the past 12 years. The National Institutes of Health (NIH) recently funded a continuation of the Phase I research in at least one more patient.

CD-ROM Makes Disability Awareness Training a Breeze

What do Canadian Airlines, Newfoundland Power, the City of Winnipeg and the University of New Brunswick have in common?

According to the New Brunswick Easter Seal March of Dimes, all of these organizations are making extensive use of Disability Awareness Training—a multimedia learning program contained on a single CD-ROM—as part of their employee orientation and training curricula.

"I attribute the CD-ROM's popularity to its user-friendliness, low cost, and the fact that companies have been waiting a

long time for a tool like the DAT program," says project coordinator Glen Hughes, Rehabilitation Technology Coordinator for the New Brunswick Easter Seal March of Dimes, developers of the program. Hughes adds that initial response has been so positive that plans are underway to launch a French version.

June Hooper, executive director of the organization, says that companies purchasing the product realize that, if they fail to treat clients and potential employees with disabilities with dignity, they will lose out in the end. "Management today must en-

sure that they can respond to the needs of this changing face of consumers without embarrassing themselves and losing good business prospects," says Hooper.

The CD-ROM, which sells for \$49.95, covers vision, hearing, mobility and speech impairments. With sections including video clips, simulations, tips and facts, situations with solutions, and multiple choice quizzes to test for knowledge gained, the user's learning experience is interesting and fun.

Sections can be completed all at once or separately, allowing for a flexible training schedule. The

entire program is completed on the learner's computer, and therefore requires little or no supervision from the employee trainer.

Production and programming of the CD-ROM was done by students of the Courseware Authoring program at New Brunswick Community College. Funding was provided in part by Human Resources Development Canada.

Profits will help support New Brunswick Easter Seal March of Dimes services.

For more information or to order, contact the New Brunswick Easter Seal March of Dimes at 506/458-8739.

Weighing It Up

How to make exercise equipment work for you

When "Disability" is associated with fitness, many people think the only way to become fit is with specialized or rehabilitation style equipment. In some instances, for people with severely limited function, this might be the only alternative. But for the vast majority of people with a disability, specialized equipment isn't the only option.

The Rick Hansen Centre at the University of Alberta has been providing instructional fitness programs for adults with a physical disability for over 20 years. When people first hear about the Rick Hansen Centre, most envision an area stocked exclusively with adapted or specialized training apparatus. But that image couldn't be further from the truth.

One of the objectives of the Centre is to help clients apply what they have learned at the Rick Hansen Centre to another fitness facility or program of their choice. Because most of these chosen facilities don't have adapted or specialized equipment, the Centre has stocked its facility with standard fitness training equipment.

Specialized equipment is great—but there are inexpensive alternatives.



When using standard fitness equipment, creativity and knowledge of individual ability levels are valuable assets. For example, using a Velcro strap or belt can stabilize the upper body of an individual with poor balance when using an exercise machine. Simple, inexpensive ideas often provide adequate support to someone wanting to train in the facility of their choice. The key is not to limit yourself to specialized products designed exclusively for people with a disability.

A number of products directed specifically at able-bodied fitness buffs are beneficial to those with functional impairment. Lifting hooks, for example, are marketed to individuals who want to train their back muscles, but whose forearms and wrist muscles are not developed enough to provide the necessary grip to pull the weight needed to strengthen their backs. The lifting hook is basically a metal hook with a Velcro strap that wraps securely around the wrist. Once on, the lifting hook takes over for the individuals' inadequate grip giving them the ability to pull more weight.

Other products such as surgical tubing, exercise balls, home-gyms and wrist/ankle weights work well both at home or in a program setting. Many of these are inexpensive options and are available in fitness, rehabilitation or department stores in most communities. Many of these products are also portable so you can take them with you to work or while travelling.

For those of you who want to exercise in a fitness club, many of the above mentioned products enhance the experience for an individual with a disability. Much of the equipment found in fitness centres is, or can be made, accessible.

Lately, fitness equipment manufacturers have moved away from producing awkward, bulky equipment to making products easy to use for the general population. This move toward ease-of-use typically means that the equipment is easy to access and operate for most users, including individuals with a disability.

The key to being active with a disability is creativity and not setting limits on the types of equipment used to become physically fit. Try to adopt a philosophy of "if it doesn't work the first time, change something and try again." By doing this you can open up an entire range of activities that keep you fit for life.

Rick Gingras, former Director of Fitness & Lifestyle Programs at the University of Alberta's Rick Hansen Centre, is pursuing an education degree. This article first appeared in Active Living, Jan/Feb 99.

Research Award for Persons with Disabilities

Attention researchers/writers: the Standing Committee on Human Resources Development and the Status of Persons with Disabilities is inviting Canadians with disabilities to apply for the 2000 Centennial Flame Research Award.

The recipient of the \$3,000 award will have one year in which to use the money to prepare a report that focuses on the public achievement of one or more Canadians with disabilities. The award results from monies collected from the Centennial Flame Fountain in Ottawa plus any private and corporate donations made to the Centennial Flame Research Award Fund.

The competition is open to any Canadian citizen with a disability. Interested applicants should submit an outline of his or her proposed research project aimed at publicizing the achievements of a Canadian or Canadians with disabilities to the Clerk of the Committee by April 30, 2000. A letter of support by someone familiar with the applicant must accompany the submission.

The Committee will select the recipient according to a set of criteria, including the significance of the contribution of the subject of the research to public life in Canada.

For more information, contact the Office of the Clerk of the Sub-Committee on the Status of Persons with Disabilities at 613/943-8399. Information about the award is available in alternate formats.

Ability Place Promises New Partnerships

There's a problem out there among the province's rehabilitation groups, and it's not just about money. It's about the management of information; it's about making what is currently inaccessible, accessible; and it's about tearing down the walls of isolation that researchers, academics and community rehabilitation workers often find themselves working behind. Our future relies heavily on forging partnerships and sharing diminishing resources. By fostering an electronic community today, Ability Place will nurture those networks.

It was from the need to address these issues that the Ability Place project was developed.

Anne Hughson and a number of others from the University of Calgary's Department of Community Rehabilitation & Disabilities Studies pulled together a steering committee in the fall of 1998 to pursue the project. To date, over a dozen organizations have given their support.

What exactly is Ability Place? It is a community-based knowledge network which will house information and provide a forum

Question: What is the Ability Place community?

Answer: It's a virtual information and services hub for Albertans with disabilities and their families, community rehabilitation professionals and community advocates

for researchers, professionals and consumers to share research activities and community resources. Through the magic of the world wide web, users will be able to download full-text materials into their own homes and offices.

Whom will this community network serve? The list is extensive—researchers, professionals, consumers, students, persons with disabilities and their families, community rehabilitation professionals and community advocates.

What sort of groups support Ability Place? To date, partners in the project range from large organizations such as Mount Royal College, the Alberta Association for Community Living

and the J.P. Das Centre at the University of Alberta, to small, parent-based support groups such as the Gateway Association for Community Living.

What kinds of resources will be made available? This will vary from partner to partner. Some of Ability Place's more sophisticated partners are able to provide electronic access to full-text newsletters, research reports and government documents. Some are able to provide "virtual reference service," where questions may be asked over the web. Others may only be able to provide Ability Place with access to an on-line library catalogue. Our goal is to provide participating partners a dynamic forum and a collaborative environment to assist them in reaching their potential.

What about sustainability? The Ability Place committee is developing a training module for participating organizations. By teaching organizations how to develop and maintain their own web sites, Ability Place will continue to thrive into the future. Interactivity via electronic bulletin boards will be moderated by community advocates, academics, professionals and consumers, and will create a dynamic environment sustained both by the users of Ability Place and by participating organizations.

What kinds of future activities will take place? In addition to developing the site and recruiting new participants, the committee continues to liaise with rehabilitation groups at both provincial and national levels with the hope of dovetailing with similar projects—we are not the only group pulling together the scattered resources of rehab communities. Additionally, usability studies will be conducted in the spring of 2000 to ensure

Ability Place Partners

- Ability Society of Alberta
- Alberta Association for Community Living
- Alberta Association of Rehabilitation Centres
- Easter Seal Ability Council
- Educational Psychology, University of Alberta
- Alberta Children's Services Library
- Canadian Paraplegic Association (Alberta)
- Community Rehabilitation & Disabilities Studies, University of Calgary
- Vocational Research & Rehabilitation Institute
- Rehabilitation Studies, Mount Royal College
- Learning Resource Centre, Provincial Mental Health Advisory Board
- Media Learning Systems, University of Calgary
- Red Deer College
- Premier's Council on the Status of Persons with Disabilities
- Southern Alberta Brain Injury Society

all potential users are able to make use of the site.

What is expected of participating organizations? Moral support, a few hours a month of volunteered time, and electronic access to specialized libraries of information are the minimum commitments.

If you have resources that you believe will be of use to Ability Place members, or if you would like more information, contact Valerie Lawton, Abilities Place Project Coordinator by e-mail (vmlawton@home.com) or phone (403/287-0370). Though still "under construction," the Abilities Place website can be viewed online (<http://mls.ucalgary.ca/virtual/>).

Research Volunteers Needed

A U of A researcher completing a Masters of Science degree in Health Promotion is studying the experiences of women with spinal cord injury in getting sexual and reproductive health needs met during and after rehabilitation. She is seeking qualified volunteers to participate in two separate interviews of about one hour, either over the phone or at locations of the participant's choice. Questions will only be as in depth as the participant chooses them to be. Identity of all participants will remain anonymous. The information provided by participants will be used in the writing of a research paper, and to make recommendations about how sexual health services can best be provided for women with SCI. If you are interested in participating in this important study, please call and leave a message at 780/492-8661, or e-mail the researcher (mmaccabe@ualberta.ca).

Alberta Sailors Contend for Mobility Cup

Four Alberta sailors contended for victory at Mobility Cup 99, the international regatta for people with disabilities. Graham Alvey placed 5th overall. Merle Hickey and Dale Keith finished 7th and 8th respectively, and Scott Wilson finished 16th. All four are from Calgary and sail at the Disabled Sailing Association of Alberta program, located at the Glenmore Reservoir.

Toronto's Dan McCoy won for the third year in a row.

The four-day regatta, held from September 14 to 17 on Lake Ontario, ended dramatically with McCoy edging out second place finisher Zoltan Pegan of North Rocks, Australia, by a single point, and third place finisher John McRoberts, of Victoria, BC, by four points.

"The competition was incredible this year, with a number of good sailors from all over the

world," says McCoy. "It made the race that much more gratifying. The conditions were great, although the pressure was on for me to three-peat in my own town."

Results of the first two races were used to split the fleet of 64 competitors into the Gold and Silver Fleets. Both fleets then sailed three more races to determine the final placing.

The winner of the Silver Fleet was Brenda Poole of Toronto.

This year's edition of the Mobility Cup was the biggest and best yet in the nine year history of this event. With over 60 sailors from around the world taking part, the regatta was nearly twice as big as any other Mobility Cup. The competition pitted sailors against one another regardless of the kind or degree of disability in a Martin 16 class boat, of which more than 30 were on hand. Sailors competing in Mobility Cup



Regatta winner Dan McCoy

99 included paraplegics, quadriplegics, amputees, and people with multiple sclerosis and cerebral palsy. In addition to the Canadians, sailors came from Bermuda, Australia, Portugal, and the United States.

The Martin 16 is a highly stable boat that disabled sailors can steer with a joy stick and trim the sails from lines that run to a position immediately in front of

the sailor. Sip and puff technology enables the quadriplegic sailors to steer and trim sails by inhaling or exhaling into a straw.

The breathing system connects to a computerized switch, which controls an autohelm, a motorized device for tightening or releasing sail lines or turning the boat to port or starboard.

Through cruise boat charters and private boat donations, many spectators, media and sponsors were able to get out onto the race course off of Ontario Place daily. This enhanced the visibility of the event and helped to drive home the point that this is truly a sport that those with and without a disability can take part in on a level playing field.

Mobility Cup 2000 will take place in Montreal this June.

Final placing of all finishers and more information on Mobility Cup can be found on the Web site (www.mobilitycup99.org).

Accessible Fairways

Golf for people with disabilities continues to grow in popularity. Paving the way are specially adapted golf carts that allow persons with mobility impairments to get around the course and golf from a seated position. One such adapted golf cart can now be found at the Broadmoor Golf Course in Sherwood Park.

This cart was purchased through a grant from the Strathcona County Community Lottery Board.

Braden Hirsch, a volunteer with the Canadian Paraplegic Association (CPA), was instrumental in obtaining this grant. Braden is an enthusiastic golfer and is willing to provide advice to people with physical disabilities who are first-time golfers. He can be reached by contacting Guy Coulombe in CPA's Edmonton office at 780/424-6312.

Look in future issues of *Status Report* for updates about other golf courses in Alberta that support golfing for people with disabilities.

Oops and Recoups: In the last issue of *Status Report*, we told you about Calgarian Vivien Gonzales and her relief efforts in Trinidad and Tobago. The contact number for her project was listed incorrectly. The correct number is 403/233-9199.



calendar of events

April 12 - 14, 2000

Diversity World and Corporate Partners Present Wellsizing the Workplace Conference and Tradeshow. Location: Toronto. Theme: promotion of the potential and abilities of employees with disabilities. Contact: Events International Meeting Planners Inc. at 416/486-4908.

May 7 - 9, 2000

The Alberta Human Rights and Citizenship Commission on behalf of the Canadian Association of Statutory Human Rights Agencies presents a National Human Rights Conference. Location: Banff. Theme: building a human rights culture: tools for transformation. Contact ICDR at 800/378-3199.

